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Improving Access to Psychological Therapies

"Relieving distress, transforming lives"

Learning Disabilities

Positive Practice Guide



foundation for
people with
learning disabilities

September 2015

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Its aim is to inform practitioners, commissioners and all involved in IAPT in making access to people with learning disabilities possible.

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Foreword

The Improving Access to Psychological Therapies (IAPT) programme aims to provide equitable access to NICE-recommended psychological therapies to people from all sectors of the community. There is evidence that people with mild to moderate learning disabilities can benefit from the therapies offered by IAPT services, especially when reasonable adjustments are made to the way in which these therapies are delivered.

This Positive Practice Guide, which is written by experts in learning disabilities, summarises the needs of people with learning disabilities and clearly outlines the reasonable adjustments that are recommended to ensure that people with learning disabilities get the maximum benefit from treatment within an IAPT service.

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Easy Read Summary



This is a guide for people who work in 'IAPT'. They do talking therapy for people who feel down or are worried about things.



We wrote this to help staff in IAPT work better with people with learning disabilities.



This guide replaces the 2009 guide.



We know that 2% of people in England have learning disabilities.



40% of people with learning disabilities also have poor mental health.



People with learning disabilities need help when they feel down or are worried.



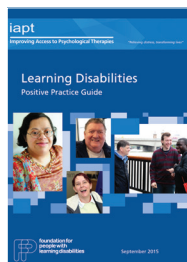
It is sometimes hard for people with learning disabilities to get good health and mental health services.



Research has said that many people with learning disabilities can use talking therapies.



IAPT cannot say no to supporting people with learning disabilities.



For IAPT staff to be able to offer good support they need to change some of the ways they work.



This is called 'reasonable adjustments' and it is part of the law that services need to make changes to include everyone.



IAPT staff have good skills but need to be more confident when working with people with learning disabilities.



Ways to make IAPT better for people with learning disabilities include:

Training which includes people with learning disabilities as trainers.



Giving people more time so they can explain what they will do together.



Giving more time to ask questions and fill in forms.



Allowing family, friends or support staff to help in therapy and help you to remember things you need to do after therapy time.



Changing rules so that IAPT and learning disability teams get to work together – then they can support more people with learning disabilities to use the IAPT service.



They need to make information easy to understand (Plain English, no jargon).



It may be better for some people with learning disabilities to get help from the learning disabilities team and not IAPT.



IQ tests should NOT be used to stop people using IAPT.



There are many people without learning disabilities who also do badly in this test. They may find reading and numbers difficult or do not speak good English.



The changes IAPT make to help people with learning disabilities will also help many other people without learning disabilities.



We want managers who plan mental health services to tell IAPT and all staff that they have to work with people with learning disabilities.



National IAPT needs to measure how well IAPT teams are doing with supporting people with learning disabilities.



If you are feeling down or worried and need help talk to your GP and ask them to tell you where there is an IAPT team.

Introduction

This positive practice guide is aimed at those who work in, commission, or refer to the Improving Access to Psychological Therapies (IAPT) services. It provides useful information regarding how best to support people with learning disabilities to access their local IAPT service, including practical examples of how some teams have made reasonable adjustments to achieve this.

Some adjustments can be made very simply, for example asking if the person requires help to complete a form during the first meeting, while others may require liaison with the local Community Team for People with Learning Disabilities (CTLTD). It will be useful for IAPT staff to be aware of their local CTLTD functions.

The National Learning Disability Professional Senate's briefing paper (2015), describes the role of the CTLTD. The CTLTD will offer the following 5 essential functions:

1. **They will support positive access to and responses from mainstream services**
2. **They will target work with individuals and services enabling others to provide effective person-centred support to people with learning disabilities and their families/carers**
3. **They will provide specialist direct clinical therapeutic support for people with complex behavioural and health support needs**
4. **They will respond positively and effectively to crisis presentations and urgent demands**
5. **They will offer quality assurance and strategic service development in support of commissioners (The National Learning Disability Professional Senate, 2015)**

The national IAPT programme was introduced by the government in England in 2005 with a clear objective of providing equitable access to psychological therapies for everyone of working age. In 2009, the IAPT taskforce published the first good practice guidance to address the needs of people with learning disabilities. This document replaces the 2009 guide and is informed by a three-year project run by the Foundation for People with Learning Disabilities (FPLD), funded by the Department of Health, which examined how best to support people with learning disabilities to access IAPT services. We are grateful to the IAPT services and CTLTDs who took part in the FPLD IAPT programme and provided the case studies and examples for this guide.

Background

It is estimated that 1,068,000 people in England have a learning disability (2% of the population) and that 145,000 have severe or profound learning disabilities (Hatton et al, 2014). (For up-to-date statistical information on people with learning disabilities visit the Improving Health and Lives Learning Disabilities Observatory <http://www.improvinghealthandlives.org.uk/numbers/>).

Most people with learning disabilities have poorer health than the rest of the population, yet despite this their access to the NHS is often limited. The 2013 *Confidential Inquiry into Premature Deaths of People with Learning Disabilities* found that people with a learning disability have a shorter life expectancy than those without: a difference of 13 years for men and 20 for women. People with a learning disability are four times more likely to die of preventable causes than the general population (Heslop et al, 2013).

People with learning disabilities are more likely to develop mental health problems than the general population. Studies screening for psychiatric symptoms in people with learning disabilities report prevalence rates of between 20.1 and 40.9% (e.g. Taylor et al, 2004), and studies using psychiatric evaluation to identify cases found a similar prevalence (e.g. Cooper et al, 2007). People with learning disabilities are a disadvantaged and vulnerable group who are likely to encounter increased psychosocial threats and also barriers to accessing healthcare, including mental healthcare. Access to the full range of treatments offered by IAPT services will enhance health outcomes for people with learning disabilities and improve the competencies of IAPT workers. The 'No Health Without Mental Health' strategy (Department of Health, 2011) and implementation framework (Department of Health, 2012) set out a vision for improving mental health and wellbeing in England and highlighted the need to ensure that mainstream services were able to include people with learning disabilities and autism and that staff in these services had appropriate skills and could provide reasonable adjustments to meet the individual needs of this group of people (NHS England, 2015).

Reasonable adjustments are a cornerstone of the Disability Discrimination Act (2005) and the Disability Equality Duty (2006). A person is disabled under the Equality Act (2010) if they have a physical or mental impairment that has a 'substantial' and 'long-term' negative effect on their ability to do normal daily activities. Reasonable adjustments are a legal requirement, not a choice, and the Equality Act (2010) places a duty on all service providers to take steps or make reasonable adjustments to avoid putting a disabled person at a substantial disadvantage when compared to a person who is not disabled. This means making adaptations to the organisation of a work environment, an educational establishment, a healthcare facility or transport service in order to remove the barriers that prevent a person with a disability from participating in an activity or receiving services on an equal basis with others.

The IAPT three-year report (Department of Health, 2012) stated: "The IAPT programme will consider that equitable access has been achieved when the proportion of patients using IAPT services is in line with both prevalence and the community profile."

This was reiterated in the *Learning Disabilities Mental Health Outcomes Charter* (NHS, 2013), which stated: "It is imperative that people with learning disabilities who have mental health needs have the same access to generic mental health services as the general population using reasonable adjustments where needed. People with mental health needs can often live normal lives if they get the right treatment and support." *The Green Light Toolkit* (Turner and Bates, 2013) is a guide aimed at improving mental health services so that they are effective in supporting people with learning disabilities. It helps services review their own quality and share and replicate good practice through a database of examples of successful reasonable adjustments made by services around the UK; the toolkit has been used by numerous IAPT services. (Please see references section on how to access free download of the Green Light Toolkit).

Understanding the needs of people with learning disabilities

According to the definition in *Valuing People* (Department of Health, 2001), a learning disability (also sometimes referred to as an intellectual disability) includes the presence of:

- a significantly reduced ability to understand new or complex information, to learn new skills, with;
- a reduced ability to cope independently;
- which started before adulthood, with a lasting effect on development.

This definition encompasses people with a broad range of disabilities. The majority are in the mild to moderate range, and a number of these function independently in many areas of their lives, though need support for more complex social tasks.

Having a learning disability can often mean that the individual has fewer psychological and material resources to deal with adversity (Jahoda et al, 2006) and is more likely to experience social exclusion, poverty and abuse (Gravell, 2012). Risk-averse service cultures contribute to restrictive environments which mean fewer opportunities for these individuals to build a sense of self-efficacy and develop problem-solving skills (Dagnan and Jahoda, 2006) and a lack of meaningful activity can increase vulnerability to mental health difficulties such as depression (Stancliffe et al, 2010).

What is the difference between a learning disability and a learning difficulty?

Distinguishing between learning disabilities and learning difficulties is a complex issue. Sometimes people use the terms interchangeably. In general, though, a learning disability is a condition that affects learning and intelligence across all areas of life, whereas a learning difficulty is a condition that makes specific areas of learning difficult, but does not affect the overall intelligence of an individual. For example, dyslexia affects only the processing of information

(usually problems with reading, writing and organising information) and not all other areas of life.

Who can access IAPT/talking therapies services?

The IAPT programme is uniquely placed within the mental healthcare pathway to support people with learning disabilities who present with depression and anxiety. Evidence suggests that people with learning disabilities can benefit from Cognitive Behaviour Therapy (CBT), particularly those with mild to moderate learning disabilities who experience depression and anxiety (Vereenoghe and Langdon, 2013). Research into talking therapies for people with learning disabilities has predominantly been into CBT. There is evidence to support the application of cognitive models (e.g. Dagnan & Jahoda, 2006), a number of individual case studies describing successful treatment using CBT, and Random Control Trials exploring interventions for anger and depression. As CBT relies on language and thinking skills, not everyone with a learning disability can benefit from such an approach (Chinn et al, 2014). Researchers and clinicians have tried to define the skills people need to be able to take part in CBT. There are core skills and circumstances that people need in order to be able to engage with cognitive therapy (Dagnan & Chadwick, 1997); these skills and circumstances include:

1. The ability to recognise a variety of emotions in themselves and others, in particular the emotions that are related to the issues they are presenting with and have the language to be able to describe these emotions.
2. For cognitive restructuring it is important that people can distinguish activating events, thoughts and emotions.
3. The ability to recognise that if people are able to change the content or

intensity of cognitions then the nature or intensity of emotion may also change.

4. Have social supports that can facilitate the learning of new skills and the engagement in new activities.

Some people with learning disabilities may find some of these skills challenging and many of the adaptations described in this document will support people who do find elements of CBT difficult to be able to use the interventions offered in IAPT services. However, as in the general population, some people with learning disabilities will find CBT difficult to use.

Research into other evidence-based therapy approaches used within IAPT services such as IPT (Interpersonal psychotherapy) and couples therapy is limited. However, this guide starts from a position which suggests that structured therapies that work for people without learning disabilities should be expected to work for people with learning disabilities unless proven otherwise. In general structured approaches work well with people with learning disabilities.

People with learning disabilities present with different needs. For some, treatment provided entirely by IAPT services will be appropriate; some will need a collaborative approach involving a CTLD and an IAPT service; while others will be treated solely by a specialist team. People with depression and anxiety without any other significant complications in their presentation and their lives will typically be able to access IAPT services, they may have contact with learning disability services and CTLDs but this may only be for statutory processes around the support they receive.

People with greater complexity, for example who may need higher levels of social support may be able to use IAPT services alongside continued specialist support of CTLDs; CTLDs will usually be very keen to engage and support the work of the IAPT services and may be able to provide support within therapy to enable generalisation and maintenance of skills acquired within IAPT treatments. However, there will be people with more severe learning disabilities and those with learning disabilities and high levels of risk or social and clinical complexity for whom it may not be appropriate for IAPT services to support. We would recommend that these distinctions are negotiated within local services.

Assumptions around meeting the needs of people with learning disabilities within IAPT services

The possible adjustments that IAPT services can make with respect to people with learning disabilities that are discussed in this practice guide are based on a number of core assumptions:

1. IAPT staff have the skills to work with people with learning disabilities. The core training for Psychological Wellbeing Practitioners (PWP) and High Intensity Therapists (HITs) develops skills that will enable them to deliver structured, cognitive-based approaches to the treatment of mild and moderate anxiety and depression that will be suitable for many people with mild and moderate learning disabilities. Based on the current evidence, there is little reason to suppose that the NICE guidance for common mental health problems (2011) will not apply to those with mild and moderate learning disabilities.
2. IAPT staff need to use these skills to promptly identify this group of people including those with learning disabilities who will be helped by adjustments and adaptations who will not always identify themselves or be identified by other services as having a learning disability. Local services should work to be able to identify people for whom reasonable adjustments should be made.

Screening, at the point of referral and other, simple strategies for identification and the ability to create 'flags' or other indicators on the IAPT data systems based upon data from other statutory data sets (for example from Primary Care, Local Authority or Specialist Learning Disability Services) will help maximise the efficiency of adaptations that are developed for this group. This is a complex process and examples of this are given later in this document.

3. The adaptations made for people with a learning disability will also help a much bigger group who are of a lower ability and who experience significant literacy and numeracy

- difficulties. Many people in the general population will have the same characteristics as people with learning disabilities but will not have been formally identified and diagnosed. Consideration of how we adapt IAPT processes and therapies for people with lower ability and with literacy and numeracy difficulties will help a large number of people who may currently struggle with access to IAPT services.
4. People with more severe learning disabilities and those with learning disabilities with greater social complexities can benefit from cognitive and other psychotherapies. However, many of the skills and service structures necessary to work with this group of people are likely to be found only in specialist learning disability teams. Therefore, increasing access to psychological services for people with learning disabilities does not mean that all people with learning disabilities will be able to benefit from them.
 5. The measurement of IQ is not a good way to decide whether someone can or cannot benefit from talking therapies and should not be used as a reason for excluding them. The adaptations used for people with low IQ scores will also help a much bigger group of people who are of lower ability and who experience significant literacy and numeracy difficulties.

Many people (approximately 16% of the population) will have the same characteristics as people with learning disabilities but will not have been formally identified and diagnosed. Please refer to Appendix 3 for more information regarding IQ and this issue.

Some people with learning disabilities will have language difficulties or other complexities that require a very specialised approach and some will not be able to access talking therapies at all. This group of people require a different approach, perhaps more like those in the Increasing Access to Psychological Therapies for People with Severe Mental Illness programmes (Jolley S., Behaviour Research and Therapy, 2015).

Reasonable adjustments

Service models

There are various models to delivering therapy services to people with learning disabilities with anxiety and/or depression. The following are examples we have seen in practice in England.

1. Equal access to mainstream IAPT services

Some services ensure that people with learning disabilities have equal access to mainstream IAPT services and that all therapists are trained to understand how their core skills can be applied to this group. In this model, an effective approach to identification, developing referral and access processes and staff training is required. The advantage of this model is that the adaptations that are made for individuals with learning disabilities can be applied to a wider group of people with low ability and literacy and numeracy difficulties. Furthermore, the data from people with learning disabilities will contribute to the overall outcomes for the service. This model forms the basis of the recommendations in this guide, although much of the guidance is relevant to all models described here.

Examples

a. In Hertfordshire Partnership NHS Foundation Trust, the IAPT teams have a single point of access for all referrals and they come from GPs, employment support organisations, voluntary services and other organisations, as well as from individuals who wish to self-refer. If other Hertfordshire Partnership NHS Foundation Trust services want to make an internal referral to the IAPT Teams they can contact the team directly and someone from the team will determine whether an assessment should be offered. Training is provided to all staff to ensure everyone is skilled up to work with people with learning disabilities.

b. In Surrey and Borders Partnership NHS Foundation Trust, there is a focus on embedding good practice and developing processes that will identify, publicise and ensure referrals to IAPT. They have developed a reference group, as part of their involvement on the FPLD IAPT programme, which includes leadership and champions from both IAPT and CTLD services, commissioners, clinical commissioning groups, generic mental health services and GPs. This group has identified the barriers to accessing IAPT services, (such as: several IAPT services in same area, only one IAPT service agreeing to be involved in supporting people with learning disabilities, no way of capturing how many people with learning disabilities are being seen by the service, need for raising awareness and training for IAPT staff, no process to flag up someone needs reasonable adjustments, triage is by telephone and not face to face, time limitations for assessments and introduction, clinical supervision), and implemented a strategic plan to address them. It has developed a number of strategies, such as organising training for IAPT staff by the CTLD, adopting the screening tool used by the Cumbria Partnership NHS Foundation Trust (see page 17) and ensuring it is available on IAPTUS, and group activities jointly run by the IAPT team and the CTLD, for example on sleep hygiene.

c. The Hammersmith and Fulham IAPT team has identified two learning disability champions, one PWP and one HIT. They work closely with the CTLD, which offers training to other IAPT staff and clinical supervision to IAPT staff when they are working with someone with a learning disability. The IAPT HIT is based for half a day a week at the CTLD building as part of the team's strategy to reach out to people with learning disabilities.

2. Specialist staff within IAPT services

It is possible to create roles within IAPT services for staff who are specifically trained and supervised to enable them to work with people with learning disabilities and who follow an IAPT process when they see this client group. This model has the advantage of ensuring that people with learning disabilities are seen within mainstream services by people with specialist skills. In addition, their data contributes to the outcomes of the service. The disadvantage of the model is that it excludes people who are not yet identified as having a learning disability. Also, the approach may not be flexible enough for rural areas where access may be a problem if specialists are not available in all parts of a service catchment. Therapists and/or clients may have to travel considerable distances to appointments.

Example

Harrow IAPT is a free, confidential NHS service which provides psychological treatment for depression and anxiety disorders for people in Harrow. It is an integrated IAPT service with a learning disabilities specialist who has been working as a HIT in the team since August 2014. All referrals are screened and triaged centrally but treatment is offered in various locations, including in GP surgeries and community settings.

3. Specialist learning disability IAPT services

It is possible to increase access to therapies for people with learning disabilities within specialist learning disabilities services. In practice the approach is similar to those in Increasing Access to Psychological Therapies for People with Severe Mental Illness programmes. This provides a service that is tailored to the needs of people with learning disabilities, and which may therefore use quite different structures, assessments and approaches from those in IAPT services. The disadvantages of this model are that data for people with learning disabilities is not included in the overall IAPT reporting process, it excludes people who are not yet identified as having a learning disability and it does not address underlying issues of equal access and mainstreaming in health services. Nevertheless, this model is compatible with the other two outlined above and could be seen as a service to complement an approach which supports people with learning disabilities to use mainstream IAPT services.

Examples

a. The Cumbria Partnership NHS Foundation Trust has improved access to mainstream IAPT services and also provided training in behavioural activation and/or guided self-help for people with learning disabilities with depression for the majority of band 5 and 6 nurses in the CTLD. This training has been developed as part of a large-scale trial but once it is completed the service will have a large pool of staff able to deliver these therapies and will incorporate them into the routine pathways.

b. 'TLC' is a specialist learning disability IAPT service in Oxleas NHS Foundation Trust, sitting between the mainstream IAPT team and the CTLD. Referrals are accepted directly from GPs and other health professionals, including the CTLD, and clients with a learning disability can self-refer. The initial assessments are usually face to face. TLC meets with both the CTLD and the mainstream IAPT service to ensure appropriate referrals. TLC is working with National IAPT colleagues to analyse their data for publications.

Referral and access

There are a number of ways in which people can access IAPT services. Some services use written referral and self-referral forms, sometimes with subsequent telephone assessments, while others encourage initial contact by telephone. There is a wide variation in the numbers of self-referrals and referrals from primary care between services, and any recommendations made here need to reflect this.

Careful consideration needs to be given to these pathways to facilitate access for people with learning disabilities. Without adaptations, it is likely that referral and access will be severely restricted for people with learning disabilities and those with lower ability and significant literacy and numeracy difficulties. Some adaptations that will support access are listed below:

1. The majority of people with formally identified learning disabilities are supported by family or paid-for carers to a greater or lesser extent. Services should allow these supporters to assist in accessing services. (Cumbria Partnership NHS Foundation Trust's IAPT service, known as First Step, emphasises on their self-referral form that people can ask somebody to help them complete the form or be present during a telephone interview.)
2. Materials such as leaflets and referral letters need to be written in an easier to read manner. Learning disability specialists should exploit their significant knowledge base and expertise in the design of accessible leaflets. (See Appendix 2 for a leaflet created by Six Degrees IAPT service and Salford Learning Disability Psychology Team. This describes their service. Also an example of an easy read appointment letter by Surrey and Borders Partnership NHS Foundation Trust.)
3. A better process for the identification of people with learning disabilities, very low ability or significant literacy and numeracy skills needs to be established, so that an open conversation can be had with individuals regarding how best to support them in completing forms and accessing the service. (See the 'Identification' section below for an example of using screening and

identification to enable sensitive access in Cumbria Partnership NHS Foundation Trust.)

An overarching principle is that forms and processes should be universally accessible to everyone requiring IAPT services. It may be that services need a range of forms for different groups, as those that are designed for people with a formally identified learning disability, such as fully pictorial leaflets, may be seen as 'condescending' for people who have significant numeracy and literacy problems but who have never identified themselves as having a learning disability. (See page 21 for easy read guidance).

Telephone interviewers should be trained to use screening or referral information, to ask key questions about literacy and numeracy and encourage and enable people to use supporters in this interaction. It may be possible in some services to offer face-to-face interviews if significant literacy and numeracy problems, which may be a significant barrier to engagement in telephone interviews, are identified.

Identification

IAPT services should give consideration to approaches that allow people with learning disabilities to be identified as early as possible in the access process. Most Primary Care and Specialist Learning Disability services have systems that validate primary care data coding of learning disability, for example the use of Reed codes to support the Quality Outcomes Framework (QOF) and systematic health checks. Learning disability services, primary care and IAPT should collaborate to ensure that referrals have Reed codes appropriately highlighted.

However, this type of system will not enable identification of people who self-refer, or those with lower ability who have not yet been identified as having a learning disability.

To address this issue, Cumbria Partnership NHS Foundation Trust's IAPT service (known as First Step) has developed a screening tool that identifies people who have literacy and numeracy needs or who have previously used learning disability services. The assessment is based upon health literacy literature and includes a simple question on learning disability service usage. This

Example: Surrey and Borders Partnership NHS Foundation Trust's adapted pathway

Stephen has moderate anxiety issues. The GP flags on the referral form to the IAPT service that he has a learning disability. The IAPT service flags him on their system to indicate that extra help may be required. The IAPT practitioner thinks about the adjustments that will need to be made for Stephen. This includes using the standard questionnaires, but with pictorial and wording adjustments to help him understand the concepts, offering him a greater number of shorter sessions, and using easy read material and pictures.

is included in one of the core IAPT data systems (IAPTUS) and is collected at the first telephone contact, along with other minimum data set information. The interviewer then adds a flag to the data system based upon responses to the screening and the therapist is given guidance on how to adapt subsequent processes accordingly. This screening has been added to the core data systems in the service and has since been adopted by a number of other services.

If they are not flagged by the referrer or through screening, services will need to rely on people identifying themselves as having a learning disability. This may result in a significant under-

identification of people with learning disabilities. In Cumbria, four people identified themselves as having a learning disability in the first two years of the IAPT service's operation. When the service matched IAPT data to other services' data on people known to have a learning disability, they discovered that in fact 75 people with a formally diagnosed learning disability had accessed the service. Guidance on asking questions about disability as a protected category in NHS services can be found at: https://www.improvinghealthandlives.org.uk/publications/1145/Have_you_got_a_learning_disability?_ Asking_the_question_and_recording_the_answer_for_NHS_healthcare_providers

	
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Within First Step we see people with a wide range of needs. We want to be as helpful as possible. Answering the following few questions will help us to best meet your needs.

1. How often do you have someone (like a family member, friend or professional) help you read letters and information leaflets?					
Never <input type="checkbox"/>	Occasionally <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Often <input type="checkbox"/>	Always <input type="checkbox"/>	
2. How often do you have problems filling out questionnaires by yourself?					
Never <input type="checkbox"/>	Occasionally <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Often <input type="checkbox"/>	Always <input type="checkbox"/>	
3. Do problems with numbers make it difficult for you to manage day-to-day activities such as paying bills and reading timetables					
Never <input type="checkbox"/>	Occasionally <input type="checkbox"/>	Sometimes <input type="checkbox"/>	Often <input type="checkbox"/>	Always <input type="checkbox"/>	

We are also trying to improve access to our service for people with learning disabilities. The following question will help us to work out how well we are doing.

4. Which of the following services have you received (please tick as many as apply)?	
Mainstream school	<input type="checkbox"/>
Specialist support unit in a mainstream school	<input type="checkbox"/>
Specialist school for people with learning disabilities	<input type="checkbox"/>
Learning disability service for adults	<input type="checkbox"/>
Other	<input type="checkbox"/>

Pathways

Once people with learning disabilities or those with significant literacy or numeracy problems have been identified, adaptations need to be made to the pathway process. At the simplest level, adjustments to the length and number of sessions should be considered. In some services, it may be possible to add time to each session for activities such as supporting clients with completion of minimum data set measures or allowing the involvement of a supporter or family member. Similar adjustments are made in IAPT guidance regarding people from minority ethnic communities who may need an interpreter. Involvement from the specialist learning disability team may be required to support the person to access the IAPT service. In some of the services who took part in the FPLD IAPT programme, people with learning disabilities were encouraged to bring a supporter/carer/parent who could help with motivation and creating understanding, and support with the homework and repetition that may be required to make therapy beneficial (e.g. Hammersmith and Fulham/West London Mental Health NHS Trust).

Examples of adjustments to mainstream IAPT pathways are listed below:

- Single point of access and assessment for the IAPT service and the CTLD.
- Common triage for the IAPT service and the CTLD.
- Include extra time for the therapy sessions (similar to that offered for ethnic minority communities to allow for interpreters). This is permitted in clinical supervision to take into account the need to read the minimum data questionnaires. In fact, Chinn et al (2014) demonstrated that many services are already allocating more time to assessments and treatment for people with learning disabilities.
- Include the Cumbria screening tool on IAPTUS or creating some other process to enable 'flagging' that someone has a learning disability to alert the clinician that reasonable adjustments will be required.
- Enable IAPT staff to access clinical supervision from specialist services such as psychologists working in CTLDs.
- Enable specialist/mainstream services to work jointly with clients with a learning disability.

- Consider reach (i.e. the processes and adjustments you need to make to ensure people know about your service and are able to use it), so that people with learning disabilities and referrers are aware that the service is inclusive.

Assessment

The IAPT minimum data sets are entirely suitable for people with learning disabilities; this includes use of the ICD-10 problem descriptors. The core clinical measures included in the minimum data set have not yet been specifically tested with people with learning disabilities and significant literacy and numeracy difficulties. However, psychometric reports of other measures of mental health show similar structures for people with and without learning disabilities (e.g. Dagnan et al, 2008). The minimum data set measures of the GAD-7, PHQ-9 and ADSMs are in general likely to be accessible if delivered sensitively.

The assessment process will vary, depending on the type of adaptations made to pathways. If possible, time should be made available in the session for the client to work through the assessment with the therapist. If this is not possible, the client may need to accept there will be less time for therapy activities as it is important to get support regarding completing the proposed measures. It is highly likely that people with difficulties in completing the measures who are not given support to do so will drop out of therapy.

Cumbria offers the following advice to therapists regarding delivering the core measures to people with learning disabilities and lower abilities:

- The core minimum data set questionnaires (GAD-7, PHQ-9, WSAS, ADSMs) may be read to the person within therapy.
- Change wording on clinical questionnaires only if necessary and then as little as possible (change one word rather than several).
- Break down questions with multiple components and deliver each element one at a time. For example the question from the GAD-7 below might be presented as: "Feeling nervous [pause], feeling anxious [pause] or feeling on edge [pause]". If the client responds to one of the elements that has been delivered, the response can be scored. If the therapist adapts the

questionnaire, they should note which element the client responded to and move on to the next question.

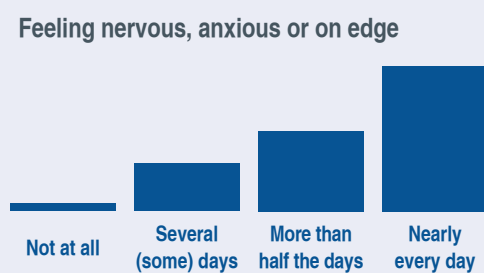
Feeling nervous, anxious or on edge?	Not at all
	Several days
	More than half the days
	Nearly every day

- Consider a simple four-point analogue visual aid for the response format or pair-wise delivery in a manner that can present as a four-point scale. The therapist asks a question that elicits a yes/no response, for example: “Over the last two weeks, have you been bothered by any of the following problems... trouble relaxing?”

If the client says no, the therapist records “Not at all”. If the client says yes, the therapist asks: “Has this been all of the time or some of the time?” If the client says “All of the time” the therapist records ‘Nearly every day’. If the client says “Some of the time”, the therapist asks: “Has this been several/a few days or a lot of the time/ more than half the days” and records the response.

This gives the four-point scale from three ‘either/or’ questions. Experience has demonstrated that this can be delivered fluently and quickly with a small amount of practice.

Over the last 2 weeks, how often have you been bothered by any of the following problems?



- Be consistent in delivery (make a note of anything you have changed and try to do the same every time you carry out the assessment with the client).

Experience of delivering them to people with learning disabilities in other contexts suggests that there is little impact on the interpretation of scores when the wording is not changed as long as the approach supports accessibility (e.g. Dagnan et al, 2008).

Treatment

A key assumption in this guidance is that therapists have the core skills required to work with people with mild and moderate learning disabilities. The CBT approaches used by HITs and the techniques used by PWP's can be adapted for people with learning disabilities and those with literacy and/or numeracy difficulties.

The core recommended adaptations for interventions are:

- Use accessible communications, easy read medication and self-help guides.
- Emphasise less cognitive elements and more behavioural elements within the intervention structure.
- Focus on delivering a small set of interventions well rather than trying to cover too many.
- Expect a significant need for repetition and, particularly when there is more than a week between sessions, the need to completely recap skills on a continuous basis.
- Consider inviting supporters into therapy for some or all of the sessions. Ensure that the supporters are properly briefed with respect to what is expected of them in the session.
- Allow extra time to involve the supporter/carer/family so that they can facilitate with homework, repetition and interpretation. The client could make an audio recording of the session, the things to practise or a reminder of their thoughts or emotions.
- Adjust the length of sessions if necessary (they may need to be shorter if concentration is a problem, or longer to cover the outcome measures and minimum data set – this is offered as a reasonable adjustment to other protected groups in IAPT services).
- Negotiate access to specialist clinical supervision for practitioners.
- Send reminders of session times, by text or telephone call, to the client, and to the supporter, so that they can plan what is needed to get the person into the therapy room.

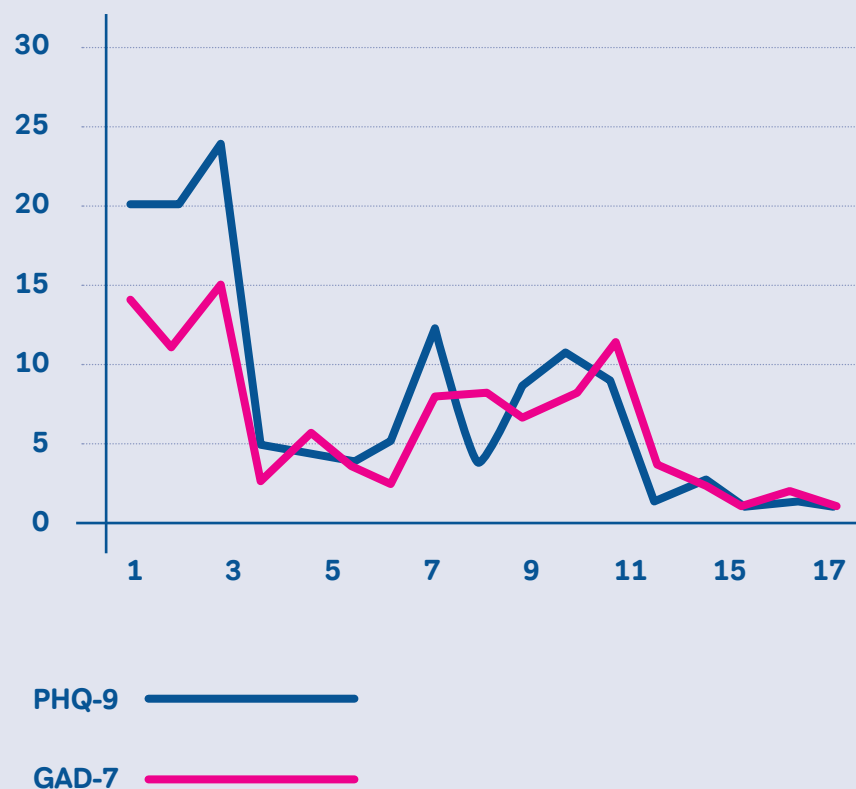
Example: extending the length of sessions (Oxleas NHS Foundation Trust TLC)

John is 72 years old and has a mild learning disability, with limited reading and writing skills. He is a widower and lives alone. He was referred to the IAPT service for help with depression. He identified his main difficulties as frequent waking, poor appetite, social isolation and general loss of enjoyment.

John attended 17 sessions of CBT with a senior PWP. His treatment plan included psycho-education around depression, sleep hygiene and medication management, in addition to behavioural activation and signposting. The following reasonable adjustments were made: all sessions were face to face; John was offered a greater number of sessions; he received regular appointment reminders; and extra time was allowed for PHQ-9 and GAD-7 outcome measures to be completed with support at each session.

Following the therapy, John reported that his sleep had improved, he was going out more regularly and he was engaging with other services locally. He spent his time doing the things that he had previously enjoyed such as visiting a café for lunch or completing word-search books and puzzles at home. He no longer experienced suicidal ideation and reported to his therapist that he felt “like a weight had been lifted”.

(The client gave his permission for this information to be used.)



Consent

Generally most people with learning disabilities will be referred via their GP, and by the time they attend their first appointment may not remember why they are there. Therefore, it is important that consent and choice are addressed during the first contact with the IAPT service, using an appropriate easy read leaflet about the service and what IAPT treatment entails.

Making information easy to read

‘Easy read’ refers to the presenting of text in an accessible, easy to understand format. In an IAPT service, this means that referral letters, leaflets about the service, minimum data set questionnaires and maps to the venue need to be adapted. Information can be adapted in various ways, but there is a general consensus (Department of Health, 2010) that the following rules should be observed:

- Text should be broken down into short sentences.
- Text should be in a large font size, minimum 14pt.
- Language should be simplified wherever possible, and any necessary complicated words or terms should be explained.

- Text should always be aligned on the right-hand side of the page, and images should be aligned on the left-hand side of the page.
- Images should be selected to represent each sentence of text where possible. An image of the therapist who will be seeing the person should be added.
- Fancy fonts and italics should be avoided.

It is recommended that photo-symbols are used in accessible materials. However, sometimes widgets or similar formats are used instead. The key advice is to use images that help the individual to understand the message you are trying to convey.

Images for easy read materials can be obtained from a variety of sources, including image banks such as Photosymbols, where you are given access to a wide range of images upon paying a (usually yearly) subscription. It is advisable to ask people who have learning disabilities to assist you when you produce easy read materials. This ensures that the resulting publication will be as accessible as possible for the target audience.



For further information see Making health and social care information accessible (NHS England, 2015). A good example of an easy read guide is *Feeling Down* – an easy read guide on looking after your mental health (FPLD, 2014). Further examples of easy read materials can be found in Appendix 2.

Example of Easy Read Information from Feeling Down Guide



How you feel when you are down, worried or depressed

Each person is different. Some people say they feel physically unwell.
Feelings (symptoms) they describe are:

 <p>Dizziness</p>	 <p>Sweaty hands</p>	 <p>Feeling tense</p>	 <p>Not sleeping Being more tired than usual, so it's hard to get up in the morning</p>
 <p>Heart beating fast</p>	 <p>Mouth ulcers</p>	 <p>Wanting to bite your fingernails</p>	 <p>Feeling sick Butterflies in the stomach Diarrhoea or stomach pains</p>

1. What is mental health? 17

Employment

One of the key aims of the IAPT programme is to keep people in employment or help them go back to work following a period of sickness absence through the provision of well-coordinated employment advice in the IAPT service model. People with learning disabilities should be encouraged to use the services of employment support workers who often work alongside IAPT teams.

In *Valuing Employment Now* (Department of Health, 2010) the importance of employment for people with learning disabilities is highlighted, yet only 7% of people with learning disabilities are in paid employment, even though most say they would like a job.

There are initiatives to help people find work, and most local authorities fund supported employment schemes for people with learning disabilities. To find the supported employment service in your area, see www.base.org.uk.

Access to Work is a government-funded scheme that provides financial support in the form of physical adjustments like building ramps and material goods such as funding for specialist equipment or a job coach when a person finds a job.

Training and developing the workforce

The importance of leadership and the role of learning disabilities champions

Effective senior clinical leadership is essential when developing a workforce who will have the confidence to support people with learning disabilities to access an IAPT service. Many services that have been involved in the FPLD IAPT programme have developed roles for learning disability champions.

Services that have done so have seen a change in the culture in the workplace. It is important to note that the champion's role is not to take on all referrals for people with a learning disability, but to liaise with the local CTLD, facilitate discussions and coordinate adaptations such as training for the IAPT team and learning disability services.

Training programmes

Training is part of continuous professional development and therapists should attend training courses based around the needs of people with learning disabilities as part of this process.

Numerous CTLDs are working with their local IAPT services to develop tailored programmes to increase therapists' knowledge and confidence in supporting clients with learning disabilities. Below is an example of such a programme.

Cumbria Partnership NHS Foundation Trust has developed and evaluated a modularised training curriculum for their PWP and HITs which has been delivered widely both within and outside the area. This curriculum was based on the extensive experience of the project group of researching and providing cognitive therapy for people with intellectual disabilities and training to therapists in this area (Dagnan and Chadwick, 1997; Dagnan et al, 2013; Dagnan et al, 2007). The curriculum is a modularised introductory programme of eight sessions, each of around 75 minutes.

The modularisation means that a core curriculum of two sessions (session 1 and a combination of sessions 3 and 5) or four sessions (sessions 1, 3, 5 and 8) can be delivered as an introductory course. The remaining four sessions (sessions 2, 4, 6 and 7) cover the key areas of adaptations to assessments and interventions more extensively.

The eight sessions in the full curriculum are:

1. Introduction to intellectual disability, epidemiology, nature and causes. Impact of literacy and numeracy difficulties in the general population. This session emphasises the importance of adaptations to therapy to people with low IQ scores and not just those with clear diagnoses of intellectual disability.
2. Stigma and its impact on therapy relationships. This session identifies the impact of intellectual disability on access to mental health services and on the formation of therapeutic alliance.
3. Introduction to the assessment of people with intellectual disabilities. This session considers the use of structured assessments with people with intellectual disabilities, and in particular focuses on the use of GAD-7 (Spitzer et al, 2006) and PHQ-9 (Löwe et al, 2004) as these are the core measures used in IAPT services in England (Clark, 2011).
4. Advanced assessment of people with intellectual disabilities. This session discusses the assessment of core abilities of people with intellectual disability associated with successful engagement in CBT (Dagnan et al, 2007).
5. Overview of adaptation of therapeutic techniques. This session identifies the interventions from the therapist's core skill set that are easiest and hardest to use with people with intellectual disabilities. It also identifies the difference between deficit- and distortion-based interventions and links to session 7.
6. Specific examples of adaptation; for example thought diaries and behavioural activation. This session gives a detailed overview of adaptation for specific interventions. The interventions may vary in this session to meet the needs of the training group.
7. Therapeutic approaches and formulation. This session considers the underlying theoretical distinctions between therapies that are deficit and distortion based (Dagnan and Chadwick, 1997) and considers the implications of this for assessment, formulation and intervention.
8. Overview of local services and discussion of communication and support systems. This session gives a detailed overview of local services and identifies pathways and support available to mainstream therapists who might need support or supervision in working with people with intellectual disabilities.

Dagnan et al (2014) describe the development of an outcome framework focused on confidence for evaluating training in this area. As stated earlier in this guide, PWP and HITs have skills that can be used to work successfully with people with learning disabilities, and it is often only lack of confidence that prevents them from using them.

Information for commissioners

IAPT services need to make reasonable adjustments to allow people with learning disabilities to access mainstream IAPT services. Commissioners will need to make adjustments to their commissioning intentions to effectively meet the needs of people with learning disabilities. Suggested adjustments include:

- Developing an understanding of local demographics in order to provide equity of access to IAPT. There are other groups, such as ethnic minorities, the elderly and the young, those living in deprived areas and LGBT people, who are finding access difficult. The different life experiences of people with learning disabilities need to be taken into account as well.
- Auditing access to talking therapies for people with learning disabilities in the same way as other people with protected characteristics.
- Introducing a screening tool to identify people needing reasonable adjustments.
- Adapting the referral form so referrers flag people with learning disabilities.
- Allowing a range of referral pathways for people with learning disabilities.
- Publicising the IAPT offer to people with learning disabilities and referrers to ensure access.
- Making it a requirement that IAPT data systems flag people with learning disabilities and the reasonable adjustments that each person requires.
- Funding ongoing training for IAPT staff to ensure that they have the confidence, competencies and expertise to assess and undertake therapy with people with learning disabilities.
- Developing a service specification that requires joint working between mainstream and specialist services.
- Adjusting the funding and data collection requirements for IAPT services to allow more time to ensure effective engagement of people with learning disabilities at referral and assessment and during therapy.
- Setting specific objectives for IAPT services and people with learning disabilities.
- Ensuring people with learning disabilities are still able to access IAPT services if they are receiving secondary care.
- Incentivising inclusion of people with learning disabilities to IAPT services through other measures such as CQUIN.
- Making reasonable adjustments a requirement and ensuring services are flexible and responsive to the needs of people with learning disabilities.

Key points for IAPT services / NHS England

- IQ score should not be used to exclude people from talking therapies. It is a relatively poor predictor of adaptations needed to enable people to access them.
- Reasonable adjustments are a requirement for all services nationally and should be audited annually, with examples of best practice shared across the organisation.
- A process for identifying and flagging people with learning disabilities should be introduced on all IAPT record systems.
- Having an evidence base on learning disability outcomes and pathways in IAPT services will help with future planning. To achieve this, specific reporting for people with learning disabilities needs to be included in IAPT data set.
- Services should consider identifying a named 'champion' in both the IAPT team and the CTLD to support the development of reasonable adjustments and good practice.
- Providers of training should incorporate modules on learning disability to be delivered jointly with people with a learning disability, for all IAPT staff, including PWPs, HITs and clinical leads. Training should be at both pre and post-qualification levels.

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Appendix 1

Research evidence: IAPT and psychological therapies and people with learning disabilities

Overview

Taylor, J. L., Lindsay, W. R., Hastings, R. P., & Hatton, C. (Eds.). (2012). Psychological therapies for adults with intellectual disabilities. John Wiley & Sons.

CBT for depression and anxiety– application and effectiveness:

Hartley, S. L., Esbensen, A. J., Shalev, R., Vincent, L. B., Mihaila, I., & Bussanich, P. (2015). Cognitive Behavioral Therapy for Depressed Adults With Mild Intellectual Disability: A Pilot Study. *Journal of Mental Health Research in Intellectual Disabilities*, 8(2), 72-97.

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Other therapies

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Different conditions

McManus, S., Treacy, M., & McGuire, B. E. (2014). Cognitive behavioural therapy for chronic pain in people with an intellectual disability: a case series using components of the Feeling Better programme. *Journal of Intellectual Disability Research*, 58(3), 296-306.

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Assessment and evaluation of treatment

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Dagnan, D., Mellor, K., & Jefferson, C. (2009). Assessment of cognitive therapy skills for people with learning disabilities. *Advances in Mental Health and Learning Disabilities*, 3(4), 25-30

Staff training

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Service Development

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Salmon, B., Gibson, S., Nagel, B., Roscoe, S., Vidalaki, V., & Ubhi, H. (2013). Offering IAPT to people with learning disabilities: Partnership working and an innovative approach. *Clinical Psychology Forum*, (252), 40-44.

Free resources

- You can download and use for free easy read CBT materials and the therapist's guide listed below from <http://www.ucl.ac.uk/psychiatry/cbt> but please cite the source: Hassiotis, A. Serfaty, M. Azam, K. Martin, S. Strydom, A., and King, M. (2012), *A Manual of Cognitive Behaviour Therapy for People with Learning Disabilities and Common Mental Disorders. Therapist Version*, London: Camden & Islington NHS Foundation Trust and University College London.

Example from the Hassiotis et al. CBT guide:










- **Feeling Down: Looking after My Mental Health, an easy read guide for people with learning disabilities** (<http://www.fpld.org.uk/content/assets/pdf/publications/feeling-down-guide.pdf?view=Standard>)

This guide is an easy read tool for people with learning disabilities to use to help them think about and take more control of their mental health, as well as help them to provide information to take to their GP.

Example from the Feeling Down guide:

Things I Feel In My Body
If you have felt these things, put a tick in the box

 <p>Pain in my tummy <input type="checkbox"/></p>	 <p>My breathing was difficult <input type="checkbox"/></p>
 <p>Pain in my head <input type="checkbox"/></p>	 <p>I was sick <input type="checkbox"/></p>
 <p>Voices in my head <input type="checkbox"/></p>	 <p>Not sleeping <input type="checkbox"/></p>
 <p>My heart beating faster <input type="checkbox"/></p>	 <p>My hands were sweaty <input type="checkbox"/></p>

3. What to do when you are worried about your mental health 52











Useful Easy Read Information

- Further guidance from FPLD on how to make information easier to read can be found at:
<http://www.fpld.org.uk/help-information/learning-disability-a-z/e/easy-read/>
- **Books Beyond Words for People with Learning Disabilities.**
<https://www.booksbeyondwords.co.uk/>
Beyond Words produces books, eBooks and other resources for people who find it easier to understand pictures than words.
- **Making health and social care information accessible** (NHS England, 2015):
<http://www.england.nhs.uk/ourwork/patients/accessibleinfo-2/>
- **Making written information easier to understand for people with learning disabilities** (Department of Health, 2010):
<https://www.gov.uk/government/publications/making-written-information-easier-to-understand-for-people-with-learning-disabilities-guidance-for-people-who-commission-or-produce-easy-read-information-revised-edition-2010>
- Photosymbols is an image bank with an annual subscription:
<http://www.photosymbols.com/>
- Change is an image bank with an annual subscription:
<http://www.changepeople.org/>
- Inspired Services Publishing is a one-stop shop for accessible information, specialising in easy read, Braille, audio, large print and translation services:
<http://www.inspiredservices.org.uk>
- Easy health can adapt materials into easy read format:
<http://www.easyhealth.org.uk/>
- Free easy read health/mental health information is available from:
<http://www.surreyhealthaction.org/>

Appendix 2


Examples of easy read information developed by IAPT practitioners

a. Sleep diary (Oxleas)

   ?	What time did I go to bed? What did I do in bed?(Read, TV, sex)
 ?  ?	What time did I put the lights out? How many minutes before I fell asleep?
  123   ? 	What time did I wake up at? Number of times I woke up? Number of hours I slept On waking up in the morning, how rested do I feel? 0 – 10 (10 most rested)

b. Example of an easy read appointment letter (Surrey and Borders)

This letter is for: Mary Smith



Meeting with Karen to talk about feeling anxious

Wed

Wednesday

Wednesday


July

8

8th July

2015

2015




11:00 am


11-00am

Where we will be meeting

Tudor Drive Day Service

For more information please contact Karen Dodd





Created at www.surreyhealthaction.org

c. Six Degrees IAPT flyer

For more information
contact:


**Six Degrees Social
Enterprise Team**

Southwood House
Greenwood Business
Centre
Regent Road
Salford M5 4QH
Tel: (0161) 212 4981
www.six-degrees.org.uk

Leaflet developed in collaboration with
Salford Learning Disability Psychology
Team
















Greater Manchester West IAPT
Salford Health NHS Foundation Trust

The
Information
Standard
Certified member



**Six Degrees Social
Enterprise Team**

For Support and Help
with Anxiety and
Depression

What can we do for you?	What is Anxiety?	What is Depression?
 <p>You can talk with one of our workers who will ask you questions</p>	 <p>When you are worried and stressed you might feel anxious</p>	 <p>Depression affects a lot of people</p>
 <p>You can talk about how you think</p>	 <p>You might feel short of breath</p>	 <p>You might feel sad or tearful</p>
 <p>You can talk about how you feel</p>	 <p>You might have a sore tummy</p>	 <p>You might feel tired and find it hard to sleep</p>
 <p>We can support you to deal with unhelpful thoughts</p>	 <p>You might feel hot</p>	 <p>You might not be interested in the things you like</p>
 <p>We can offer you ways of feeling better</p>	 <p>You might feel tingly</p>	 <p>You might find it hard to concentrate</p>

Appendix 3

Supplementary information on IQ

An IQ score is a poor predictor of whether a person can or cannot benefit from talking therapies.

IQ measurement is arbitrary and not a good basis for decisions regarding what reasonable adjustments may be required to make therapy accessible.

If 2% of the population are estimated to have an IQ score below 70, in a group of 500,000 adults, this would amount to 10,000 people (8,000 adults). However, most services estimate that they only know of about 20% of the people in their area who could have IQ scores below 70, which would be just 1600–2000 (<https://www.improvinghealthandlives.org.uk/>). This means that there may be around 8000 adults living within a population of 500,000 with IQ scores below 70 who are not formally identified as people with learning disabilities.

These people are very likely to be already receiving specialist health and mental health care and being treated more or less successfully.

However, the ‘cut-off’ of an IQ of 70 for identifying a learning disability is relatively arbitrary; there is no difference between the adaptations we would want to make for a person with an IQ score just below 70 and someone with an IQ score just above 70. In fact, as stated above, IQ is a relatively poor predictor of adaptations required to enable people to access psychological therapy.

People with IQ scores between 70 and 85 are likely to benefit from some of the adaptations we might introduce for people with learning disabilities. Although these are not the same population, the proportion of people with IQ scores below 85 is the same as the proportion of people in the UK considered to be functionally illiterate. (See Illiterate adults in England – National Literacy Trust. http://www.literacytrust.org.uk/adult_literacy/illiterate_adults_in_england).

In an adult population of about 500,000, we would expect about 80,000 people (16% or 1 in 6) to have IQ scores below 85 and/or have difficulty with literacy and numeracy. We would therefore expect that at least 1 in 6 people receiving specialist mental health services or in general hospital wards would have IQ scores below 85.

It is likely that a greater proportion of this group of people will engage less well in IAPT therapies and drop out of therapy before completion than the rest of the population. The literature on factors that affect outcome in IAPT therapies suggests that engagement and completion of therapy is a significant factor in predicting outcome. If the adaptations enable a small number of people to stay in therapy and move towards recovery, it is likely that this will support improved recovery data following intervention. Even in large services the denominator in recovery calculation is such that 10–15 extra people moving towards recovery each month will improve the recovery data for a service by at least 1 or 2%.



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